

Town Hall Meetings
Comments and Suggestions
Patient Issues

Comments

- Anne Arundel County Department of Health's web page has games for all ages that educate them on cancer prevention. www.aahd.org
- Persons with good insurance have a primary care provider who refers the person to the other specialist. Do not have that for individuals who come through programs at Health Department so we look at the organ (that is funded at the time) not at the whole person.
- Medicaid will pay for surgery but will not pay for an oral exam for a diagnosis.
- No full-time person assigned for fitness and nutrition at Maryland State Department of Education.
- The work and screenings cannot be done until persons are more secure with the providers.
- Work schedules of many Asian persons (many are employed in the evenings) are another reason that persons cannot be reached. The response is low when persons cannot come due to working in the evenings or to programs held mainly in the daytime when they sleep.
- Obtaining transportation is a difficult problem for many people. There is a need to find ways to provide transportation.
- Learning about what is important requires that you utilize the persons in the community who can speak the language.
- For instance MDs need to have special times to take cultural sensitivity training because of their hours of work.
- Many people do not know and are scared to even find out the facts about cancer.
- Charles County is fighting a battle with a killer running rampant but residents do not want to take the time to hear the information.
- Once cancer is in the family, people become more active. We must find a way to make it a concern before it hits home.
- Cancer is an epidemic and must be treated as such.
- People cannot get to treatment. Some are even walking or paying enormous fees for transportation and still cannot get the medication or treatment.
- Research is not paying attention since the guidelines give an older age for screening and we are seeing younger people who have cancer and are dying.
- Doctors do not know when to stop or say no to more treatment. The clinical setting patients keep getting the treatment far longer than needed.
- How are guidelines and standards created and then implemented? Are they legislated?
- Are any of the panels or members of the Cancer Control Council on the guideline-setting panel?

- Education is needed on cancer signs, symptoms, screenings, treatment and how to use the health care system.
- Partnerships are critical system for effective education.
- Language barriers are critical problems to adequately addressing cancer issues.
- Low-income populations do not have money to get to screening or follow up.
- It is difficult for a provider to give care to persons who come from another area.
- The Maryland Hospital Association been involved in the Cancer Council Planning process and all hospitals are encouraged to participate.
- Translation of materials is critical and money is not available to do this, (e.g., if some one gets into the treatment program, they get a letter telling them that they can get Medicaid. The letter states when and where to apply. Many of those who get the letters cannot read English or simply cannot read).
- A new program targeting the Asian populations will be available in both Montgomery and Prince George's Counties.
- There are translated materials in other states but Maryland is not producing translated materials here nor using the materials that are available.
- No follow up can be done because of limited funding.
- Events are held but cannot follow-up with individuals due to language barriers and the lack of funding.
- Children are diagnosed late, (e.g., children are taken to emergency rooms or pediatrician offices that do not know that there are many kinds of childhood cancers).
- Cancer Council needs to recognize the increase of cancer in the aging population as well as in children.
- Prevention should be the target issue in midlife age range.
- Cancer prevention should be a required in health education in schools.
- There is a long wait list for care for the Asian population.
- Many people do not know what insurance they have or if they know they have it do not know what it covers.
- Patient Issues Committee has representatives from two hospitals as members.
- Each ethnicity has the same issues and all need to share what and how they have dealt with the issues.
- Howard County will pilot a program in the schools that will focus on seven cancers, patient needs, family issues, and cancers in youth.
- Web is available for resource information but then clients don't have transportation to get to where the services are offered.
- Many people will not go to other sites because they are afraid.
- Information is needed for providers so they can obtain the services needed for the patient.
- Persons need to use the Cancer Council Town Meeting initiative to get what they need in the plan.
- The Department of Health and Mental Hygiene's 800 number was originally set up as a Breast & Cervical Cancer Hotline. It now gets calls on all cancers and is developing a list of resources.
- The Cancer Society has assessed every community as to availability of resources.

- Mid-Atlantic Cancer Society has a Patient Navigator Program that uses Licensed Social Workers to provide the services.
- Entertainment education (using artist to present the education) has occurred in other countries but it is not being used here.
- Community hospitals are doing the care. Get the information from them and not from the research centers.
- Maryland has set up a long-term follow up for adult survivors.
- There should be a way to interact and learn all the systems in near by counties.
- People are being turned off by the type and number of questions asked in order to be screened.
- Cancer transforms ones entire life. Even the new psychosocial model still does not meet all the needs of a patient. Trying to get the help hinders the healing.
- Many patients cannot continue their work after diagnosis and during and after treatment. However, there is no occupational support for retraining.
- Education is critical. We must know the resources and how to find them.
- Some resources are not known until it is too late to be of assistance.
- The Wellness Community is an example of an organization that gives all it can to each person.
- People need to realize that life can be livable with cancer.
- Nurses and doctors are so overworked that they do not have time to learn all the resources.
- Collaboration is critical, work with all organizations.
- Chase Brexton does PAP tests and other screenings. The outreach and just taking the time to listen makes a difference in a client's response. 10 % of our clients are now going regularly for screenings.
- Prevention is critical but people need to know that the screener is interested and will talk with them
- People do not know programs exist.
- Do not forget the transportation concerns.
- Volunteers have liability issues when they drive patients.
- Johns Hopkins Hospital's name is coming up again and again as not screening a person if the client owes money to the hospital.
- There is outreach to get both men and women into the screenings. If what you are telling us is the case, it needs to be taken to the appropriate persons.
- People are being turned off by the type and number of questions asked in order to be screened.
- There are forms that must be filled out. As screeners we must respond to the funding source and regulations regarding what we are doing.
- There is a report done to the legislators and they want the information on what is happening. If we want to be refunded we must comply.
- We want to make people aware of what the Cancer Society does. We improve the quality of life for cancer patients by getting them resources and information.
- Partnerships we have are varied and we want to form more.
- The Cancer Society can identify resources that are needed and can field questions for groups that are not able to do it for themselves.

- All the Western Maryland organizations and resources have been linked but there is still a lack of resources.
- Med Bank takes 6-8 weeks to obtain the service.
- Garrett County uses United Way funds to give short term funding for medications.
- Resources are available for the indigent but not for those who work and/or have insurance.
- Insurance companies are cutting back on what they will pay.
- Patients do not have enough money for the alternative treatments.
- Insurances, Medicaid and Medicare have cut back and do not pay for new drugs. This impacts the research on treatments and new drugs.
- When a patient cannot pay, the physician will select another drug that may not be as effective but is available to the patient through his insurance.
- Allegany now has a Cancer Coalition, which includes all the key players.
- Breast, cervical, prostate, colorectal, skin, and oral cancer screenings are available.
- Patients referred but no arrangements are made.
- Emphasis on genetic counseling, but we do not have enough people to recruit a genetic counselor to our area.
- Pediatric oncology is an issue. Children go to Baltimore for treatment and then are given follow up at home. But this is a limited number since we do not have the network to coordinate services.
- Even short distances take a long time due to the roads.
- Community is open to education and prevention but do not know what to do if diagnosed.
- People have Medicaid cards but local physicians will not accept their cards for screening examinations.
- Frederick sends patients to other counties for screening because no physician in Frederick will take their insurance.
- Colonoscopy screening does not screen persons with symptoms in some counties.
- State needs to understand that even when a patient is diagnosed, they do not go directly into treatment.
- Patient Navigators would be a perfect addition.
- Medical system is broken and there will be a tremendous crisis of care within the next five years.
- \$40 billion a year spent for paper work, which would pay for all uninsured in the country.
- Limited reimbursement money for physicians to screens for patients' means that physicians will not volunteer.
- Hours per week are spent doing paper work required for the small amount of reimbursement.
- Medical assistance rates for the screenings are so low that it is hard to find physicians to do the screenings.
- \$5 million was added to Medical Assistance budget but only for physical exams not to do screenings.

- Cancer cannot be segmented, we need to know where to reach people for one cancer risk but we can then be comprehensive and focus on all others that might impact the person.
- Transportation is a huge problem.
- Accessing treatment is a problem since there are not enough physicians to serve the persons with medical assistance cards.
- Medicaid should also pay for the other things that cancer patients need, (e.g., Patients are exhausted from the treatments but still need to come to hospital for treatment for nausea or other treatment connected problems).
- There are an insufficient number of specialists on the Shore so persons needing specialist must travel to Baltimore for treatment.
- Patient records must be returned when they are treated elsewhere or the local hospital does not know what the treatment, side effects, or other problems may have occurred.
- Caroline County is even more rural than the rest of the shore counties.
- There is not one head or neck surgeon on the Shore.
- Non-emergency care for patients is needed, as is the use of telemedicine, training for providers, dental care and follow up for all the other aspects of health that are not done by the specialist. Treatment dollars need to go with these.
- Cannot reach all the people so must do the best you can.
- Council needs to see if there are cancer clusters and then do a campaign to target the area and educate the persons in those communities.
- Patient Navigators and a clearinghouse are critical since it is time consuming to find what is out there.
- Committee Meetings should be held in areas other than Baltimore.

Suggestions

- Create a state web site.
- Need State media campaign on cancer issues.
- Screen for everything that the patient might have for their age, race, sex, etc., not just for an organ.
- Obtain information from Illinois regarding their program.
- Urge Community hospitals to do outreach in these areas.
- Need an alternative way to deliver information to the community using items that suite the culture.
- Positive reinforcements such as peer reinforcement, bus tokens, foods, like a birthday cake, and other giveaways will work.
- Use primary and secondary reinforcements.
- Create ways to finance or provide transportation.
- Address the specific needs of the Hispanic community and learn the real issues that concern them.
- Need increased education on cultural issues.
- More payment for extra time to see clients from other cultures that may not speak English.

- Require or mandate training on cultural sensitivity especially for health professionals.
- Increase communication within the community between the health system and the residents.
- Have more town meetings and listen to what is said by all residents.
- Talk to the people in their communities and have them tell us how to make a difference in their communities.
- Target communities and key people who could deliver the message.
- Bring a Wellmobile into Charles County to reach, with prevention and care programs, the people who cannot get to us.
- Make more money available to help people navigate the system once they are diagnosed.
- Get together with the churches so that they can educate and assist their members.
- Refer names of health care experts to the State task force that creates the guidelines for colon, skin, and breast cancer.
- Ask that the guidelines be reevaluated. For instance, the colorectal screening guidelines were reevaluated and the task force decided to continue the original guidelines.
- Ask the political candidates how they stand on the issues.
- Fund all screening mandates.
- Ban together to talk to the people who direct the programs to put the emphasis on the local needs.
- Submit bills in the County and get them up to the General Assembly.
- Use available model programs whenever possible.
- Ask the Council to remember that childhood cancer is an important issue.
- Assist the providers to find the resources the client needs.
- Research the issues of late effects for cancer survivors.
- Recruit patients for the late effects research as they leave the institutions so the system can follow them.
- Use the cross-cultural approach to ethnicity.
- Need Patient Navigators who can help patients at all levels.
- Share the resource books available on all cancer care with all national, state, and local resources.
- Use the Cancer Society's Patient Navigator Program located in the Mid-Atlantic division by calling 301-933-9350
- Stop relying on other associations to work with the Native American populations and do direct outreach to them.
- Need an across the board approach to cooperative partnerships.
- Increase and refine communication among all programs.
- Write grants to get have electronic bulletin board and post information from all resources..
- Keep the Cancer Control Council web page up and running and in a fluid state.
- Work with community agencies to get groups to meet and exchange information.
- Educate the artist and they will take prevention information to the youth.
- Look at what representation from community hospital is on the Cancer Council Planning committees.

- Be inclusive of all communities and use the video conferencing techniques for committee meetings.
- Need vouchers for cancer patients or survivors in urban and suburban areas so they can make it to follow up or care.
- Arrange convenient timing of the services making them convenient for all persons.
- Create a listing of the cancer related legislation passed in Maryland, Virginia, and D.C.
- Educate patients that Clinical trials are available and how to participate.
- Develop guidelines for how to move through the cancer experience.
- Need a person at the state level to provide information on what all the counties have as resources and to connect all the groups on a regular basis.
- Have a web site for providers to get the information and then share it with patients.
- Recommend that education be provided on what occurs during the screening, what will happen if there is a diagnosis, and if there is no cancer diagnosed how long to wait until a re-screen should be done.
- Provide occupational support for retraining for persons with cancer.
- Encourage the Wellness Community to assist providers to know the resources so they may tell their patients about them.
- See all persons regardless of income as is done at Chase Brexton.
- Recruit more cancer patients to participate in the planning and ongoing oversight of the Cancer Council Plan.
- Need funding for transportation.
- Consider using the public shuttle buses that come to many neighborhoods at the request of seniors.
- Give transportation vouchers to the patients.
- Use the services that exist but use them better.
- Provide or fund places for cancer patients to get away from it all for a week. The activities could include information on diet, massage, support therapy, group discussions, and other programs. Cancer Society does have a volunteer transportation program but it is limited.
- Use and publish the Cancer Society information number (888-227-6333). Trained counselors are there every day that can assist patients.
- Partner with the clients, recognize that they want to be heard and included.
- Need to know where and how to access resources for all cancer patients.
- Sensitize doctors so that they tell the patient what is available that meets their special needs and then tells them where to find it.
- Publish and give information on how to contact the drug companies that give free medications to patients.
- Use the volunteer driver organization in the Cancer Society.
- Mandate the registration of all programs in the state and create a directory of services.
- Legislate the same reimbursement rates that Medicare pays for colorectal cancer.
- Pay for biopsy of oral lesions as well as polyps.
- Create a screening to treat the whole person, not organs.
- Create a single payor system.
- Need incentive so that physicians will take patients.

- Increase the Medicaid rates paid for screenings.
- Decrease for the provider and the patient, the complexity of getting the funds.
- Need to find resources for those who fall through the cracks, move, or have no fixed address.
- Need a resource to fill that time gap until Med Bank provides medications.
- Suggest that United Way be contacted to see if it can provide a way to help with short term funding for medications
- Propose legislation to have the insurances and Medicaid and care pay for the oral chemotherapy.
- Use funds with in the system that comes from donations to pay for some medications.
- Educate health providers on the resources and on how to make the referrals.
- Assist patients with information on how to make the arrangements for referrals.
- Lobby local coalitions and health department to set a reasonable rate for what the patient must pay.
- Tap into treatment dollars, if there are treatment dollars, to provide screenings for persons with no symptoms.
- Use other resources when there is no treatment money.
- Recruit more cancer specialists to Western Maryland.
- Work to increase trust by community member of the providers
- Provide the opportunity for second opinions and access to clinical trials.
- Assist the creation of a mechanism to have academic systems set up clinical trials.
- Fund treatment centers for western Maryland including for pediatric oncology.
- Conduct localized, joint screenings for the area and let the patient know where to go for help
- Change the funding structure so that money can be moved as needed.
- Seek a Medicaid waiver to loosen the regulations, change recall rates and allow a more fluid use of the money.
- Simplify the guidelines and consent form.
- Get a panel of experts to work on a single consent form for all systems.
- Lobby for Health Care for All to create a good system for all patients.
- Need to find what the interests of the churches are, ministers will help you if you go to their church or provide them with incentives
- Need to identify who is providing what services. Patient Navigator programs would be consistent with the idea of know what resources are really there for us to use.
- Start so there is no duplication and that we can use models that are successful
- Do age appropriate screenings.
- Educate the public on the levels of insurance that exist.
- Pay for patients to have care at home for secondary cancer problems.
- Educate providers and patients about medications and all aspects of cancer care.
- Secure increased funding at a high level for residents and Fellows (who are underpaid) so they will come to the Shore.
- Support Fellows if they will return to Shore area to practice.
- Allow communities to spend the cancer money to bring needed specialists to their areas.

- Support all health providers and encourage them to learn about cancer and the needs of the patient.
- Arrange to have major hospitals send residents and Fellows to hold clinics, do surgery, and teach the local physicians.
- Reduce the stress of the patients by not having them travel to Baltimore where everything is different, new, and dangerous.
- Increase the pool of physicians who will serve Medical Assistance Patients.
- Use new ideas like health fairs, with screenings and referrals, to educate the community regarding these issues.